

INDIANA

Breaking Down Barriers: A Success Story for the ICC Clinical Trials Action Team

Currently, only 3% to 5% of adult cancer patients enroll in a clinical trial. Without clinical trial participation, breakthroughs and advanced treatments do not occur. In 2008, 20 states had legislation in place mandating that insurance companies cover the routine patient care costs for cancer patients enrolled in clinical trials. Indiana was not one of those 20 states. The Indiana Cancer Consortium (ICC) decided to address this issue.

The ICC is a statewide network of public and private organizations working to reduce the cancer burden in Indiana. This organization seeks to increase cancer prevention activities; increase early detection of cancer; decrease barriers resulting in disparities of access, screening, and treatment; and increase quality of life for cancer patients through increased communication and collaboration of ICC member organizations. The ICC Steering Committee formed an action team to address barriers to clinical trial participation in Indiana, recruiting subject matter experts to identify solutions. With that, the ICC Clinical Trials Action Team was born—including individuals from various organizations such as the American Cancer Society (ACS), Leukemia and Lymphoma Society (LLS), St. Francis Hospital, Northern Indiana Cancer Research Consortium, and more.

After much debate regarding barriers to enrollment in clinical trials, the Clinical Trials Action Team decided to promote legislation during the 2009 Indiana General Assembly, HB 1382. This legislation would mandate insurance companies cover routine patient care costs for cancer patients enrolled in clinical trials. Routine patient care costs include blood work, physician visits, and services related to the disease, but not necessarily the clinical trial. Such care costs would not include the drugs or research-related expenditures associated with a clinical trial, which typically are incurred by the clinical trial sponsor. During the latter half of 2008, the Clinical Trials Action Team geared up to mobilize support across Indiana and generate interest from state legislators, along with the public.

The legislative process began fairly smoothly. There was a great deal of interest from both chambers, and this issue reached across party lines. Rep. Peggy Welch and Sen. Beverly Gard were the first sponsors of the bill. Both were passionate about getting HB 1382 passed, working together to develop a strategic plan to make this law.

Unfortunately, a minor challenge developed regarding the fiscal impact of HB 1382. The Legislative Services Agency (LSA) solicited top Indiana insurers to configure the cost of this legislation to the state. The insurers reported to LSA that this bill would cost thousands of dollars. The Clinical Trials Action Team knew this number was inaccurate and disputed the insurers' estimate. Numerous studies have shown that routine patient care in clinical trials costs insurance companies about the same, if not less. After the Action Team configured its estimates and provided data, LSA realized the inaccuracy of the initial figure. In the end, HB 1382 had no fiscal impact whatsoever. This was a small success in the process for the Action Team.

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Toward the end of the legislative process, the insurance companies realized HB 1382 was heavily supported and likely to pass. They worked with ACS and LLS to negotiate the details of the bill. The insurance companies wanted a hold harmless clause so they would not be liable if the clinical trial did not work for the cancer patient. ACS and LLS added it to the legislation. When all parties agreed, the insurance companies supported the bill.

When the legislation went to the floor, it passed unanimously. In fact, one legislator said he had never

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voted for a mandate before in his career, but he felt it did not make sense to be against this bill. The Clinical Trials Action Team's efforts paid off. HB

1382 was enacted and signed by Gov. Mitch Daniels on May 7, 2009. On July 1, 2009, this legislation became law!

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